Fluctuating Physical Function and Health: Their Role at the End of Life

June R. Lunney, PhD, RN,¹ Steven M. Albert, PhD,² Robert Boudreau, PhD,³ Diane Ives, MPH,³
Anne B. Newman, MD,³ Tamara Harris, MD⁴ and for the Health ABC Study

Abstract

Background: Our recent research suggests that a fluctuating trajectory, previously thought to be the experience of those dying with heart failure or chronic lung disease, may not accurately characterize the end of life for these patients.

Objective: We sought to further examine health and function to investigate whether other measures or a different time frame captures the purported exacerbation/recovery trajectory associated with these diseases.

Design: Function and health data were collected prospectively at six-month intervals for 17 years during the Health, Aging and Body Composition Study.

Subjects and Measures: We analyzed self-reported mobility, health status, and health care utilization for 1410 decedents, defining high fluctuations as transitions in two or more adjacent assessment pairs during the last three years of life.

Results: Among decedents, only 207 (14.7%) reported two or more changes in mobility during the last three years of life; and 586 (41.6%) reported more than two transitions in self-reported health during the period. This fluctuation was not associated with any clinical condition in the three years before death, but decedents with chronic heart failure or chronic lung disease reported significantly more changes in mobility (odds ratio = 1.15, $p = 0.025$) for a longer follow-up period. Decedents with heart failure were also more likely to report hospital stays in the last three years of life.

Conclusions: Fluctuations in mobility and self-reported health do not differ by clinical condition in the three years before death, but people dying with chronic heart failure or chronic lung disease are more frequently hospitalized during this period and experience more unstable mobility for a longer period of observation.

Keywords: heart failure; lung disease; mobility; trajectories

IN AN EARLY STUDY of patients dying in a hospital, Glaser and Strauss described an “entry–reentry” trajectory of dying, where patients seemed to be dying but instead recovered and were discharged.¹ Subsequently, graphical depictions of dying trajectories have generally included one with fluctuating function,^{2,3} ascribing it to organ failure based on the known pattern of disease exacerbations with chronic heart failure and lung disease. Quantitative analyses to investigate dying trajectories have generally involved statistical methods that correct for fluctuation rather than identify it,^{4–6} but our recent research suggested that fluctuation in physical function was not a characteristic of those dying of chronic heart failure or lung

disease.⁷ Thus, we sought to further examine fluctuations in physical function and self-reported health and their relationships to end-of-life trajectories.

Methods

Sample

We derived our analytic sample from the Health, Aging and Body Composition (Health ABC) panel study. At baseline, the cohort of 3075 participants was 48.4% male and 41.6% black. Background on the cohort is available at (<https://healthabc.nia.nih.gov>).

¹Hospice and Palliative Nurses Association, Pittsburgh, Pennsylvania.

²Interdisciplinary Studies of Aging Section, Laboratory of Epidemiology and Population Studies, Department of Behavioral and Community Health Sciences, University of Pittsburgh, Pittsburgh, Pennsylvania.

³Department of Epidemiology, Graduate School of Public Health, University of Pittsburgh, Pittsburgh, Pennsylvania.

⁴Laboratory of Epidemiology and Population Sciences, NIA, Bethesda, Maryland.

Accepted October 25, 2018.

By the completion of year 17 of the study, 1991 participants were identified as deceased. Of these, 1555 had been interviewed six months before death. Our final analytic sample ($n=1410$) comprised the subset of these who died in year 4 of the study or later, allowing three years of data for assessment of disability trajectories.

The institutional review boards at the University of Pittsburgh, University of Tennessee Health Science Center, and University of California at San Francisco approved the study protocol, and written informed consent was obtained from all participants.

Measures

Health ABC participants were interviewed every six months during the 17 years of the study. Questions regularly captured self-reported mobility (difficulty walking a quarter mile or climbing 10 steps), independence in activities of daily living (ADLs) (neither needing equipment to get around nor help with bathing, dressing, or transferring), self-reported health status (scaled from 1 poor to 5 excellent), health care utilization (self-reported nursing home stays and hospitalizations), and chronic illnesses (self-report of physician diagnoses). To examine fluctuations, we counted the number of changes in response to questions between two adjacent assessments (separated by six months).

Missing data were challenging for interviews conducted during the last three years of life. The results obtained from multiple imputation approaches produced very similar results to simply counting transitions. We present counted transitions.

Analyses

To examine the last three years of life, we reordered the prospectively collected data to represent observations at six-monthly intervals before death, that is, death-minus-6-months, death-minus-12-months, and so on. Basic analyses included frequency distribution, chi-square comparison among groups, and one-way analysis of variance.

To further examine the role of fluctuating health and function during the last three years of life and across decedents' entire period of study participation, we modeled the proportion of transitions among nonmissing assessment pairs

using binomial logistic regression combined with overdispersion terms that accounted for correlations between transitions. Relative increases in the odds of a mobility transition at any given assessment were evaluated for the different decedent groups adjusted for baseline age, gender, and the length of time observed. Statistical analyses were conducted using SAS version 9.3 (SAS Institute, Inc., Cary, NC).

Results

Table 1 summarizes characteristics of the total analytic sample and of decedents grouped by the counted frequency of transitions in mobility difficulty during the last three years of life (0 or 1 transition, 2 or more, and 3 or more). Among the 1410 decedents in the analytic sample, 207 (14.7%) reported two or more changes in their ability to walk a quarter mile without difficulty during the last three years of life. Frequent fluctuations were not associated with any specific clinical condition in bivariate analyses. Regression models that adjusted for age at death, gender, and the number of nonmissing assessment pairs also found no significant differences among decedents in the odds of more than two transitions across groups defined by clinical conditions. Compared with all other decedents, the odds ratio (OR) for those with chronic heart failure (CHF) was 1.0 ($p=0.68$) and for lung disease 0.97 ($p=0.77$).

Complete data were much less available for transitions in ADL disability, defined as the need for equipment to get around or assistance with bathing, dressing, and transferring. Twenty-seven (2%) reported more than two changes in the last three years of life, and these decedents did not differ in disease prevalence or demographic characteristics.

Fluctuations in health were reported more frequently than in mobility: 586 decedents (41.6%) reported more than two transitions in self-reported health during the final three years of life. As with mobility, this fluctuation was not associated with any specific clinical condition.

Fluctuation and hospitalization

We examined the relationships between transitions in self-reported health or function and reporting a hospitalization during the six months previous to the assessment. Overall, decedents who reported more than two transitions in mobility

TABLE 1. CHARACTERISTICS OF DECEDENTS GROUPED BY NUMBER OF TRANSITIONS IN MOBILITY DIFFICULTY IN THE LAST THREE YEARS OF LIFE

	All decedents ($n=1410$)	Decedents with no transitions ($n=874$)	Decedents with one transition ($n=329$)	Decedents with two or more transitions ($n=207$)
% Female ($X=9.2$, $p=0.01$)	46.9	50.0	42.6	40.6
% African American ($X=6.8$, $p=0.03$)	40.7	40.6	36.5	47.8
Mean age at death (SD) ($F=10.7$, $p<0.0001$)	84.7 (4.7)	85.0 (4.8)	84.6 (4.8)	83.3 (4.5)
Self-reported comorbidity				
% With lung disease	20.1	20.4	17.0	24.2
% With diabetes	28.2	29.8	26.1	24.6
% With chronic heart failure	19.5	19.3	19.3	20.3
% With cancer	27.2	25.9	32.2	20.6
% With no mobility difficulty three years before death ($X=86.2$, $p<0.0001$)	55.8	46.9	80.6	53.1

SD, standard deviation.

difficulty or self-reported health during the final three years of life did not report inpatient hospital stays more frequently in the six months before each assessment ($p=0.08$). Among decedents with organ failure (either CHF or chronic lung disease), only those with CHF more frequently reported hospital stays ($p<0.0001$). At each assessment point, these previously hospitalized decedents with CHF also more frequently reported a decline in mobility or persistent mobility difficulty ($p<0.0001$).

Fluctuation and clinical conditions: longer follow-up and multivariate models

Controlling for baseline age, gender, and the length of time observed, participants with CHF reported significantly more changes in mobility (OR = 1.15 higher odds of a transition at any given time point, $p=0.025$) when transitions were examined for their entire participation in the Health ABC Study. Likewise, participants with chronic obstructive pulmonary disease also exhibited higher odds for transitions between assessments (OR = 1.18, $p=0.011$) for the longer period.

Discussion

Congruent with published clinical guidelines that describe diseases punctuated by exacerbations,⁸ we found greater fluctuation in physical function among Health ABC participants with organ failure (defined as chronic heart failure or chronic lung disease) over the course of the study. However, compared with other decedents, those dying with these diseases did not report more frequent transitions in mobility or self-reported health in the three years leading up to death. These findings surprised us but suggest that associating a fluctuating end-of-life trajectory of physical function or health for these decedents may be misleading.

Other investigators have also challenged the “organ failure” trajectory. Gott et al.⁹ found no “typical trajectory” among 27 decedents who died of heart failure in their study, although the various trajectories presented all contained multiple peaks and valleys. Fluctuations in health had been suggested by findings from the SUPPORT study, where investigators found that more than half of those hospitalized with organ failure (chronic obstructive lung disease, congestive heart failure, or end-stage liver disease) who met criteria for hospice eligibility were later discharged and survived more than six months.¹⁰ Yet a follow-up study of the heart failure patients who survived the index hospitalization found no fluctuation in ADL independence among those who died within the next year.¹¹

Several study limitations could explain why we did not observe more transitions in the last three years of life for decedents with chronic heart failure or lung disease. In addition to the problem of missing data, the timing of our data collection (every six months) could have missed transitions associated with decedents’ last hospital stays. In addition, with little data about ADL independence, we depended upon self-reported difficulty walking a quarter mile. This may not be the best indicator of fluctuating physical function in the final years of life if respondents answer in the abstract about

an untested ability and have denied or not observed the subtle progression of their chronic disease. Finally, we use data from a larger study designed for other purposes.

Although reports of fluctuating mobility did differ before the end of life for decedents with chronic heart failure and chronic lung disease, our inability to detect frequent transitions in the last three years before death challenges the use of a fluctuating trajectory to describe function at the end of life for these individuals. More research is needed to determine if study limitations adequately explain our findings or if self-reported health and function change infrequently in the final years of life for those with heart and lung disease.

Author Disclosure Statement

No competing financial interests exist.

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Address correspondence to:

June R. Lunney, PhD, RN
Hospital and Palliative Nurses Association
Pittsburgh, PA

E-mail: june@lunney.org